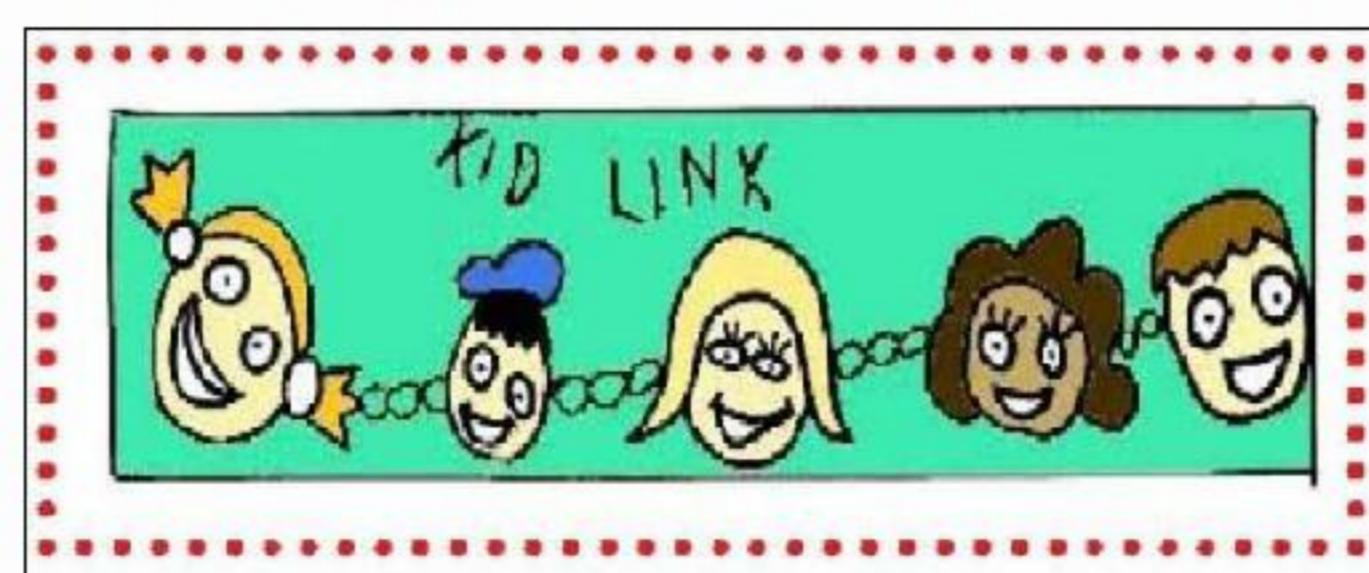
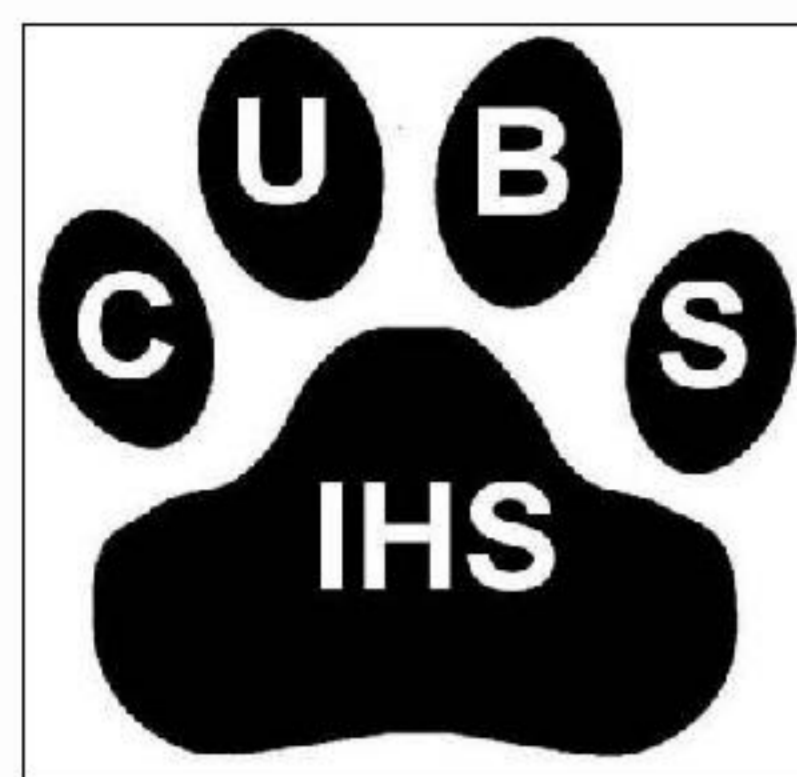


# Participation of Children in National Haemophilia Conferences

The Irish Haemophilia Society provides support and education to members on various issues relating to their bleeding disorder through three main conferences each year. In 1998, the I.H.S. introduced a children's programme to allow parents attend the sessions at our conferences. Starting with just four children, the programme has since developed into four age specific children and young adult's groups with an average of 52 children attending each conference, starting with our crèche group at 0 – 3 years, Cubs Group 4 – 7 years, Kidlink Group 8 – 12 years and Youth Group 13 – 18 years.

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Irish Haemophilia Society



Initially, the aims of these groups were solely to provide supervision. However, as time has progressed the educational aspect has become more important. Since the introduction of the children's groups in 1998 we have seen many children progress through the different children's groups and become young adults with a clear understanding and acceptance of their bleeding disorder. These groups not only serve an educational purpose, but have also created an enhanced community where people with haemophilia and their siblings can feel comfortable discussing and sharing any issues they may have. A testament to the success of the programme is that many of the children who attended the programme are now volunteer leaders; passing on their advice and support to the younger generation. Of the 37 volunteers we now have volunteering with the society 12 previously attended the children's programmes. This is beneficial not just due to the advice and experience the volunteers can pass on to the younger children, but also adds to the level of empathy and understanding our volunteer leaders can bring to their work and foster in the children.

The programmes themselves are designed by a dedicated children's programmes co-ordinator who provides a structured yet fun approach to learning and education not only for the children with bleeding disorders, but also for siblings and children of adults with haemophilia. Each group begins the conference with team building exercises. This allows the group, who may not know each other, to bond and create a supportive environment for the various other sessions and workshops which the groups will take part in over the course of the weekend. While it is important to have an element of entertainment and fun, which will help encourage and develop friendships and social support, this is also the perfect environment to educate the children on aspects of their or their family member's bleeding disorder in an age appropriate manner. Over the past number of years some of the programme highlights have included:

- Podcasts on various aspects of life with a bleeding disorder
- Movie animation workshop on life with haemophilia
- Puppet Shows
- Team Building Exercises
- Workbook exercises with both an educational and entertaining element
- Adventure weekends for our youth group members

With regular evaluations of all the programmes it is the aim of the Society that the content is consistently relevant, informative and appealing to the target groups.

